

STATE OF SURVIVORSHIP

SURVEY: 2021



NATIONAL COALITION
FOR CANCER SURVIVORSHIP

INTRODUCTION



The National Coalition for Cancer Survivorship (NCCS) conducts an annual State of Survivorship Survey, in partnership with Edge Research, to delve into the cancer patient and survivor journey. This study captures a range of perspectives to better understand how NCCS can support its mission to advocate for quality cancer care for all.

Conducted in the spring of 2021, the research helps NCCS build on and track findings from the previous year to better understand the differences in patient and survivor attitudes, experiences, and needs. Through 16 in-depth interviews* and a nationwide survey of 1,604 patients and survivors, 500 of whom have a connection to NCCS, this survey illustrates the experiences and impact cancer treatment and care has for survivors. Survey respondents in the national sample represent a wide range of stages of diagnosis, demographics, socioeconomic levels, and available support systems, using quotas to make sure the sample was representative of cancer patients nationally by age, gender, race/ethnicity, and region (based on data from the American Cancer Society and National Cancer Institute). All data presented are from the national sample (n=1104) unless otherwise noted.

The data repeatedly show that cancer treatment has a disproportional effect on lower-income, Hispanic/Latino, women, and younger patients between the ages of 18-39. Metastatic and/or Stage IV patients consistently view cancer care

with a much different, and often more intense, lens. We also found that respondents with a connection to NCCS consistently had higher expectations in their assessments of quality care, were more likely to feel empowered to be active in their care, and were better able to find a range of support systems.

This report will demonstrate how these consistent themes present themselves within the key finding areas of: Disparities in Quality of Care, Costs of Cancer Care, Support Systems, and Treatment During COVID-19. It will also look at what the word “survivor” means to those who are, or have been, on a cancer journey.

NCCS’ mission is to advocate for quality cancer care for all people touched by cancer. The data in this survey demonstrate an urgent and ongoing need to service this mission. The differentials between NCCS-connected respondents and the national sample reinforce this need. Not all who receive a cancer diagnosis are afforded the opportunity to become educated about cancer or feel empowered to be active in their care. While many of the NCCS-connected respondents may be better positioned to navigate their cancer journey, the unique circumstances of each individual should not be a roadblock to better patient experiences and outcomes. Everyone diagnosed with cancer should have comprehensive, consistent, and coordinated care, regardless of their ability to advocate for themselves.

* Stories and quotes throughout this report are direct from a selection of these 16 interviewees, but names have been changed for privacy.

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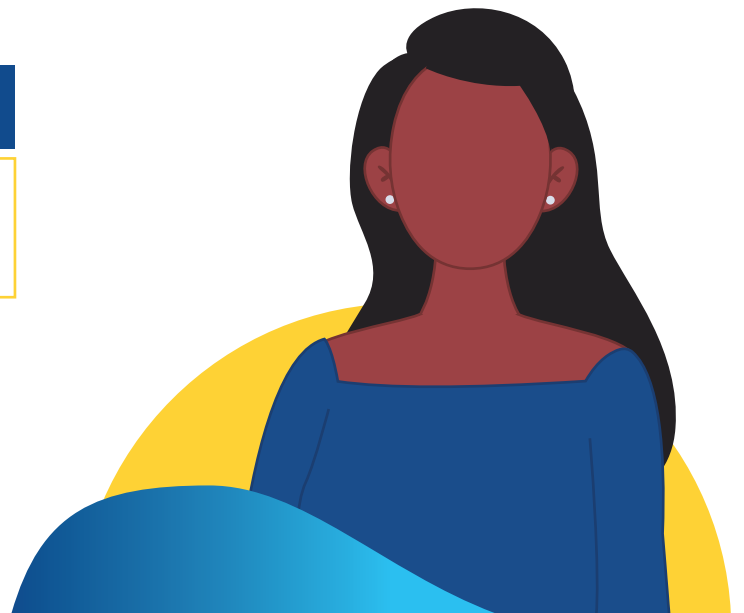
DISPARITIES IN QUALITY OF CARE

Most cancer patients describe their cancer treatment and care as excellent and believe their health care providers (HCPs) were approachable, respectful, and coordinated their care well. Though for many, their threshold is making it through their treatment. But there are consistent disparities, with younger, Hispanic/Latino, female, and low-income patients having consistently poorer experiences. There are also differences between metastatic patients and those still in treatment, compared with those who have completed treatment.

Camila is a mother of two and was 32 when she was diagnosed with Stage II ovarian cancer. Her struggle to get a proper diagnosis is one shared by many younger cancer patients, as well as Hispanic/Latino patients. She had pain in her right ovary and was given a variety of diagnoses, including a urinary tract infection, bladder infection, and bacterial infection. After months of her pain worsening while on antibiotics, and multiple visits to urgent care and her primary care physician, she refused to leave her provider's office and insisted on an ultrasound. The transvaginal ultrasound showed a 12cm tumor that turned out to be cancerous.

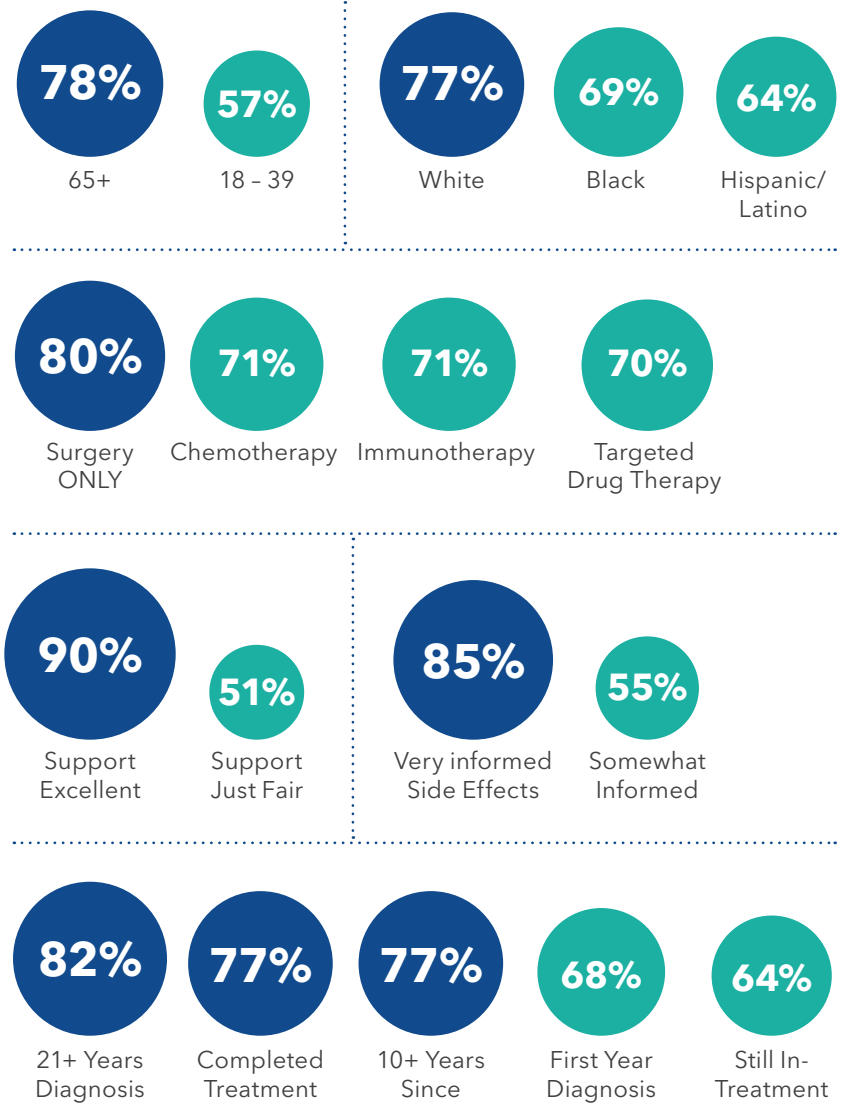
"I am alive, period."

#1 Reason to describe cancer treatment and care as excellent.



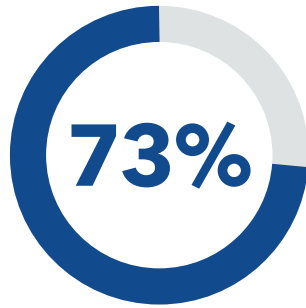
Even with the substantial challenges she faced in receiving a diagnosis, Camila felt her treatment was excellent. She did have many questions throughout, but said her HCPs were able to answer them and they listened to her concerns with care. She is part of the 64% of Hispanic/Latino patients who rated their care as excellent. However, compared to 69% of Blacks and 77% of whites who rated their care as excellent, there is a clear difference in satisfaction with their care.

Respondents Who Rated Their Cancer Care as Excellent



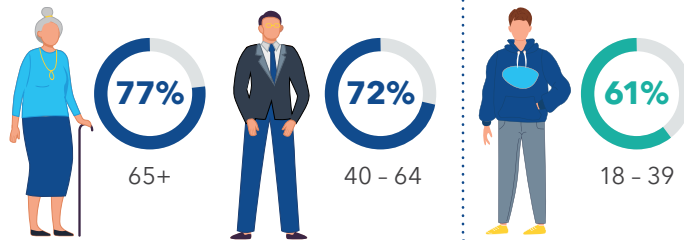
Differences were evident in patients' relationships with their HCPs. When asked if they felt their HCPs listened to their questions and concerns, only 63% of Hispanic/Latino patients said yes compared to 75% of their white and 73% of their Black counterparts.

Relationships with Health Care Providers



Felt their HCPs respected their questions and concerns

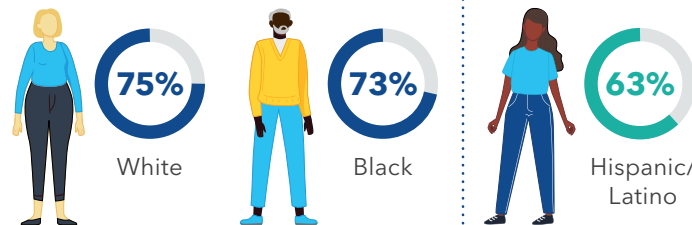
AGE DIFFERENCES



I feel like they keep things from me because I won't understand.

They were always in a rush or assumed I didn't know what I was talking about, meanwhile I am a health care professional myself.

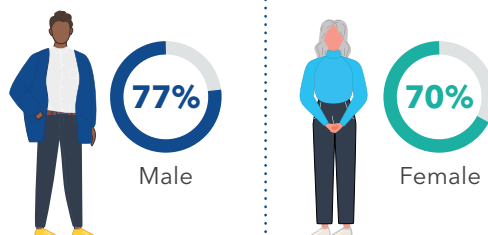
ETHNIC DIFFERENCES



Again, some of the doctors, all of them white and male, seemed to project their biases onto me.

Sometimes, my doctors would simply ignore my questions or even give me attitude if I had a lot of questions.

GENDER DIFFERENCES



He kept telling me I was overreacting and to follow up in 6 months.

Dismissing me out of hand regarding pain—don't feel as a middle-aged woman I am heard.

"Oh yeah, that happens." Not even a word of sympathy or encouragement.

As Camila went through surgery to remove her tumor and her subsequent chemotherapy, she said she felt heard, particularly by her chemotherapy nurse who was with her throughout the process. She was informed of the myriad side effects that were possible and did in fact experience several, including hair loss, nausea, extreme fatigue, and muscle and joint pain. While almost all patients experience at least one side effect, the data show again that female, Hispanic/Latino, younger and low-income patients are more likely to experience many of the side effects.

Top Symptoms Experienced

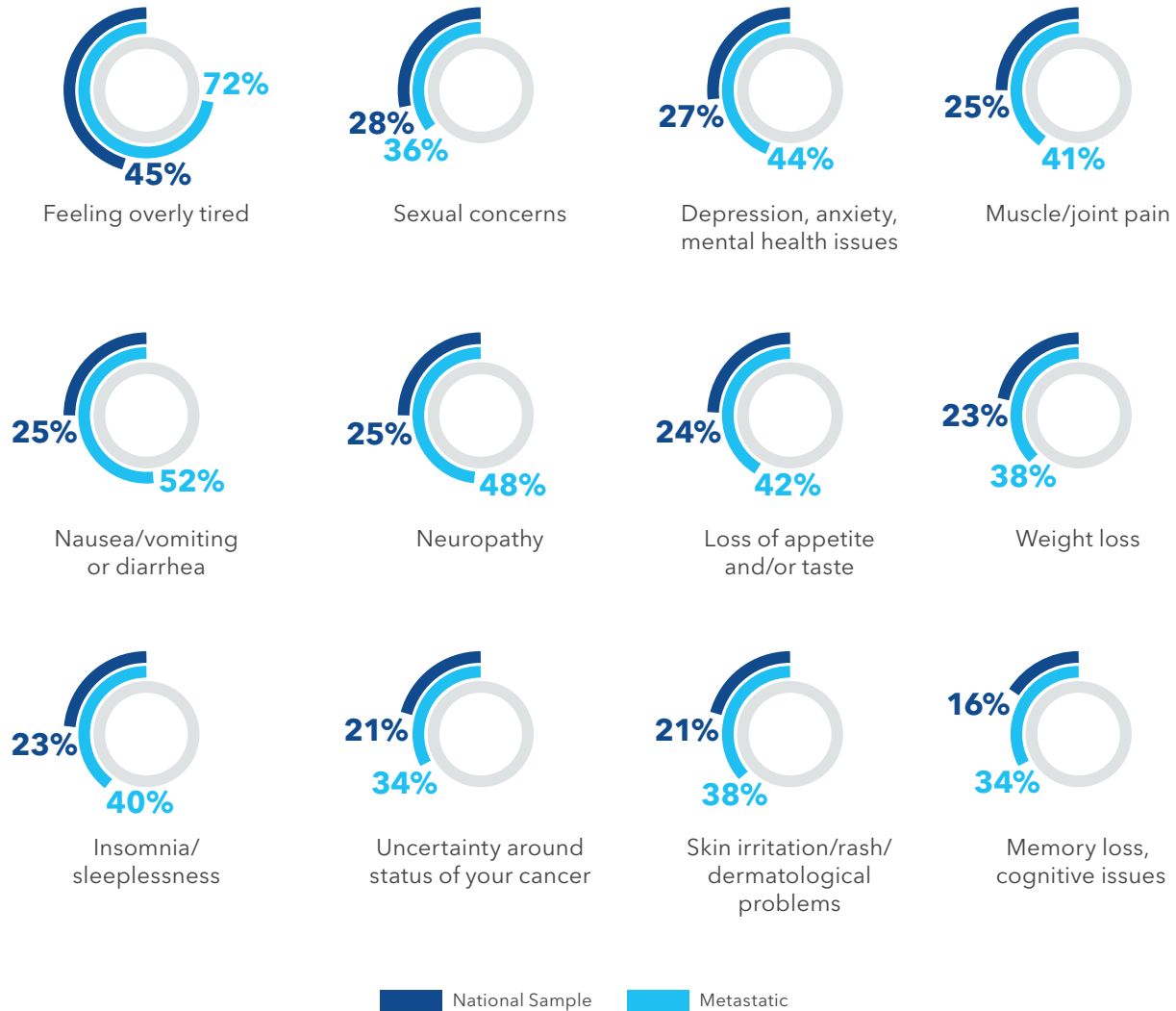


of Patients experienced at least one symptom

	National Sample	Male	Female	18 - 39	Hispanic/Latino	Low Income
Feeling overly tired	45%	34%	56%	61%	53%	57%
Sexual concerns	28%	38%	19%	27%	26%	17%
Depression, anxiety, mental health issues	27%	17%	37%	52%	43%	43%
Muscle/joint pain	25%	16%	34%	39%	33%	40%
Nausea/vomiting or diarrhea	25%	17%	33%	56%	33%	38%
Neuropathy	25%	18%	31%	40%	28%	33%
Loss of appetite and/or taste	24%	18%	30%	48%	32%	34%
Weight loss	23%	24%	23%	53%	38%	31%
Insomnia/sleeplessness	23%	14%	31%	40%	36%	28%
Uncertainty around status of your cancer	21%	21%	21%	26%	21%	28%
Skin irritation/rash/dermatological problems	21%	12%	29%	30%	22%	22%
Memory loss, cognitive issues	16%	7%	25%	33%	30%	24%

Not surprisingly, side effects are more commonly reported by metastatic patients. Of the 12 top side effects reported, metastatic patients experienced all or most of them at an average of 18 percentage points more than other respondents. Fatigue and nausea were each experienced by 27 percentage points more by metastatic patients than non-metastatic.

Metastatic Patients Experience More Symptoms than the National Sample



While two-thirds of patients felt informed about side effects, in most cases less than half felt their HCPs were very helpful in addressing them. The side effects HCPs were most helpful with were nausea/vomiting or diarrhea and dermatological issues, both of which have effective treatments. This suggests room for improving how to address more nuanced side effects of cancer treatments, particularly memory loss and cognitive issues (30% reported their HCPs were very helpful), sexual concerns (35% said their HCPs were very helpful), and fatigue, the top reported symptom (46% reported their HCPs were very helpful).

These findings are consistent with our surveys from 2019 and 2020. Of note, the percentage of respondents who said their HCPs were very helpful went up in 2021 for a number of the top symptoms reported.

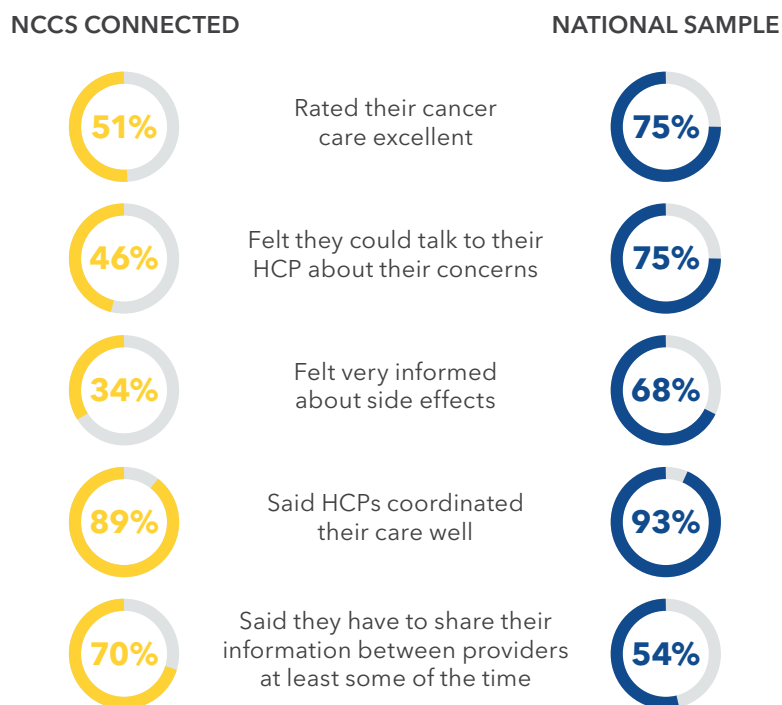


While two-thirds felt informed about side effects, in most cases less than half believe their HCP was very helpful in addressing them.

Once Camila finished her chemotherapy, she began regimented two-month check-ins for scans and bloodwork. More than two years into her post-treatment care, her doctors continue to find no evidence of disease. Interestingly, while 75% of respondents said their cancer care was excellent, only 63% say the same about their post-treatment care. That percentage is much lower among NCCS-connected respondents with only 38% saying their post-treatment care is excellent.

Survivors connected to NCCS in the survey were, as a whole, less satisfied with their care compared to the national sample on a range of measures, including quality of care, coordination of care, feeling informed about side effects and communication with HCPs.

Higher Expectations/Lower Satisfaction for Connected Patients



The data show that the work NCCS does to help survivors advocate for equity in, and access to, quality care helps them look at their treatment and post-treatment with a critical eye of what “quality care” truly means. The data also show we have much work to do to increase opportunities for quality care for all who are touched by cancer.



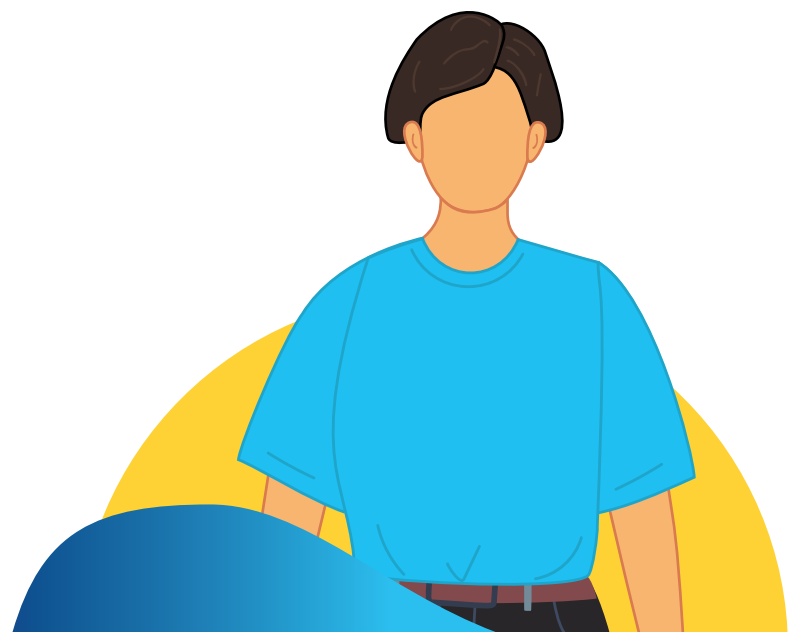
COSTS OF CANCER CARE

When the excruciating pain in Bethany's right arm caused her to pass out while getting dressed, she ended up in the emergency room. The attending physician told her the arm had spontaneously broken because of a lesion on the bone. Eventually diagnosed with multiple myeloma, Bethany quickly discovered the many costs of cancer.

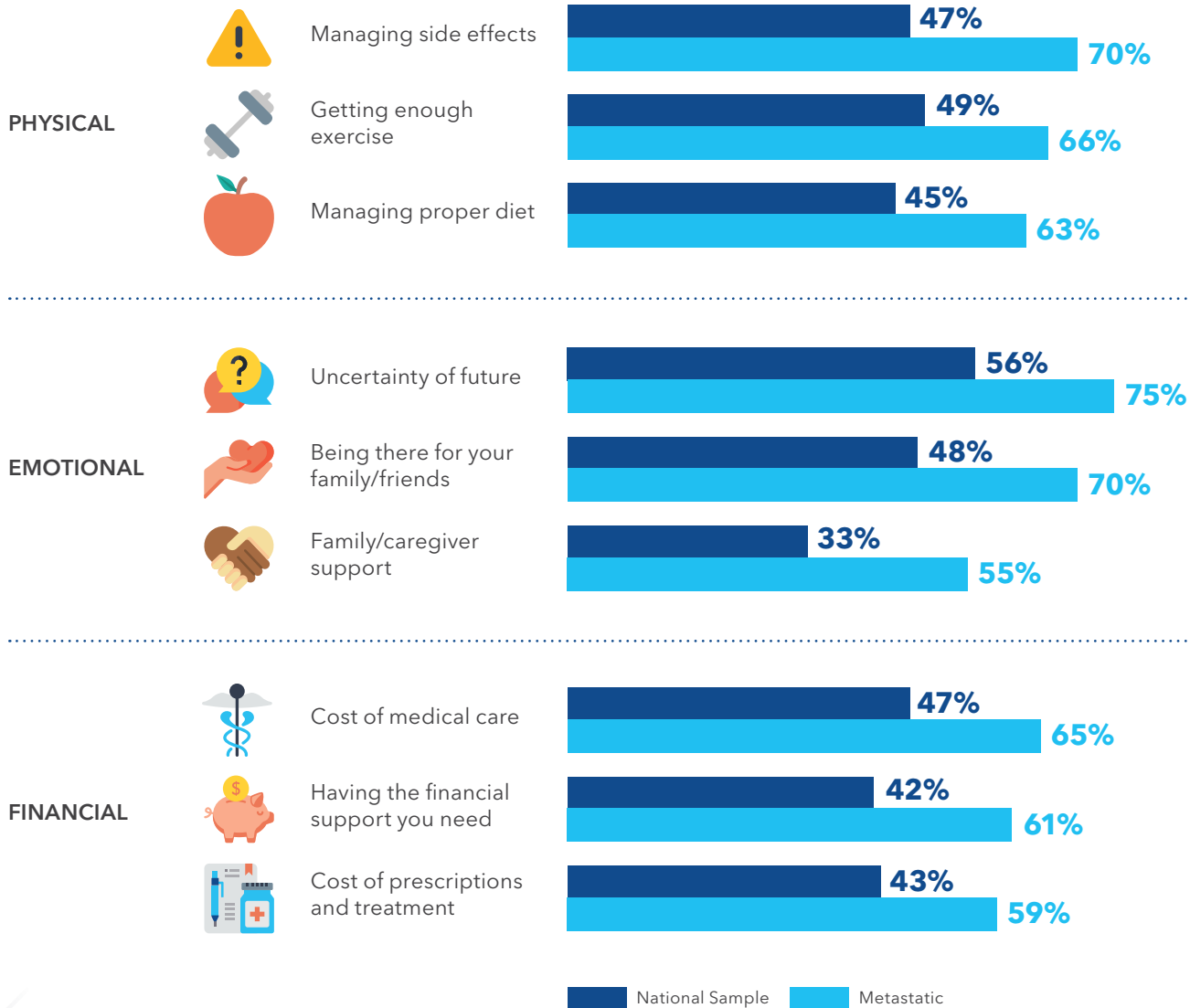
To most, the word "cost" has a financial association. This is, of course, true for cancer patients as 47% of our survey respondents cited the cost of medical care as a concern. But the cost of cancer goes far beyond the financial and insurance concerns for many respondents. A variety of physical and emotional health concerns are also major concerns. Half of our respondents were concerned about simply having enough energy for the day. Over half cited uncertainty about the future as their top concern. For patients with advanced cancer, like Bethany, the emotional strain that comes with an uncertain future is the top concern for 75% of respondents.

47%

Respondents who cited the cost of medical care as a concern.



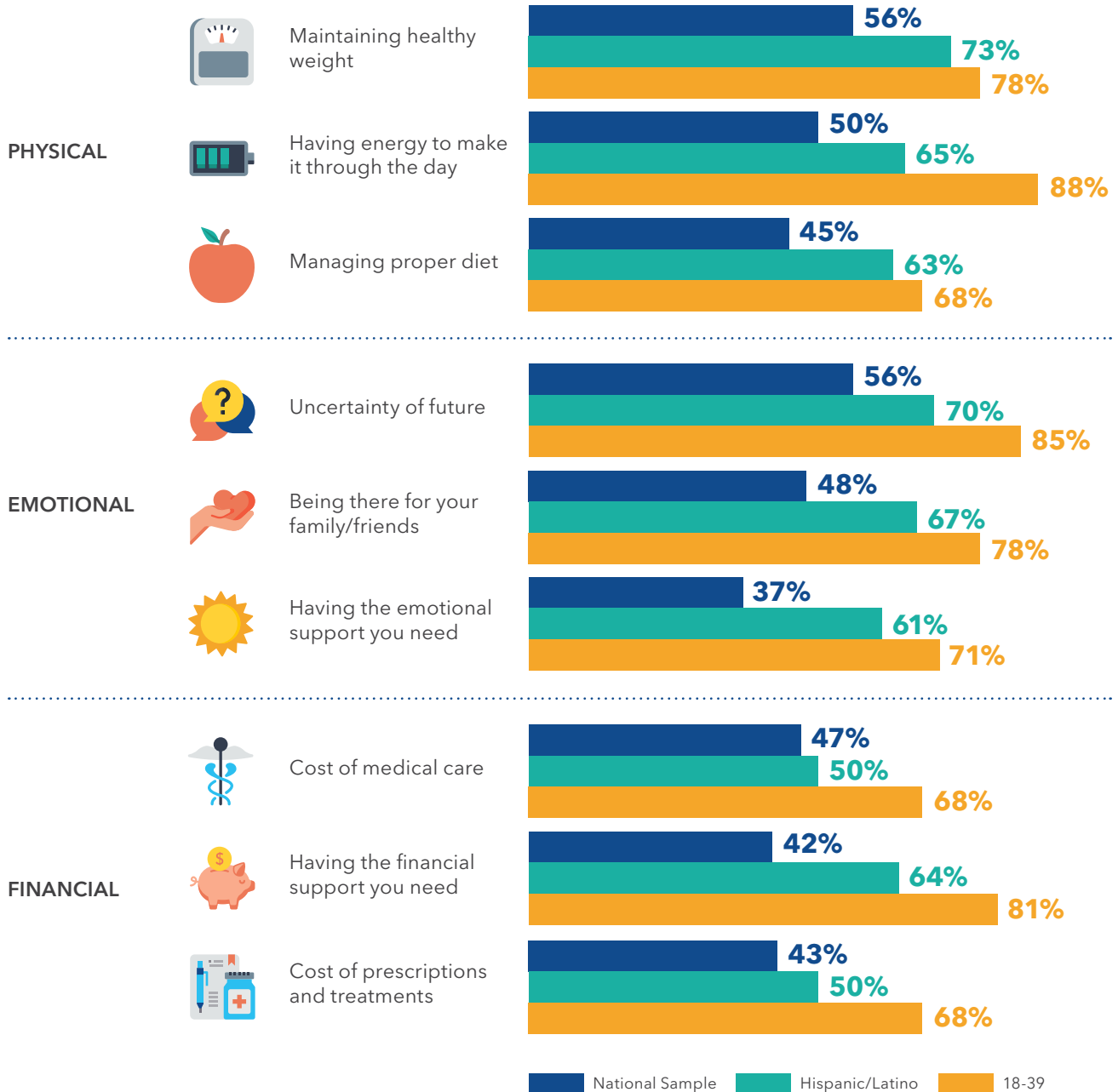
Cancer Survivors' Top Concerns



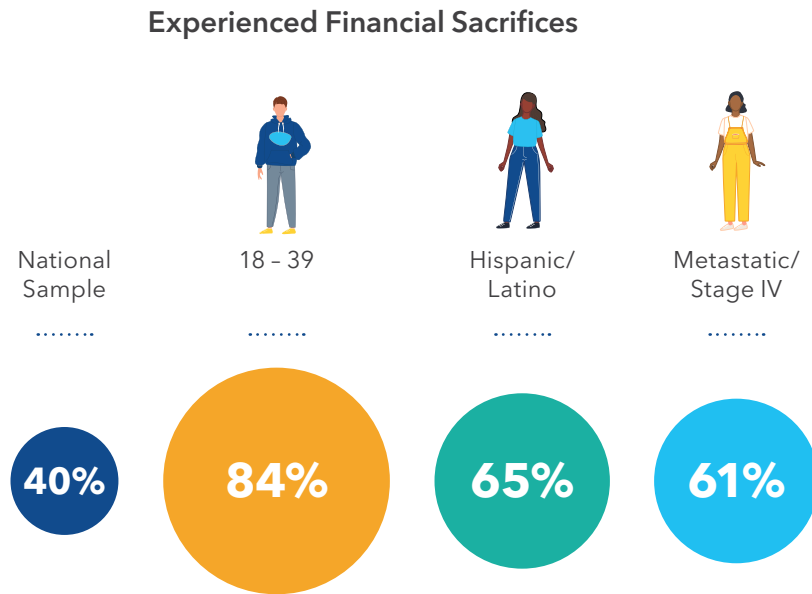
After 25 years of public-school teaching, Bethany was nearing retirement. Teaching was a second career for her, and she loved it dearly. She planned to work for another seven years. However, with a variety of ongoing side effects and physical limitations that caused her to often miss class, she decided to retire. She says she will earn less than half of her full salary moving forward but is grateful she got this far in her life and career before her diagnosis.

Younger (ages 18-39) and Hispanic/Latino respondents have higher physical, emotional, and financial concerns compared to the national sample. Having emotional support, financial support, and the energy to make it through the day rated much higher as concerns for younger and Hispanic/Latino respondents than the national sample.

Hispanic/Latino and Younger Patients Have Higher Concerns than the National Sample



Financial concerns led to changes in behaviors or sacrifices for many respondents. Of the national sample, 40% said they experienced at least one financial sacrifice like spending savings or retirement money for living expenses, delaying a major life event like marriage or having children, delaying a major purchase, or reducing payments to existing debt. We continue to see significant differences in how vulnerable groups experience these financial sacrifices, with 84% of younger patients, 65% of Hispanic/Latino, and 61% of Metastatic/Stage IV patients reporting they experienced at least one of these sacrifices.



The costs of cancer are many. Our survey shows that vulnerable patients are much more likely to experience these costs. The advocacy and work NCCS does is as urgent as ever. Our survey clearly shows we must continue to work with policymakers on equitable solutions to address the physical, financial, and emotional costs of cancer.



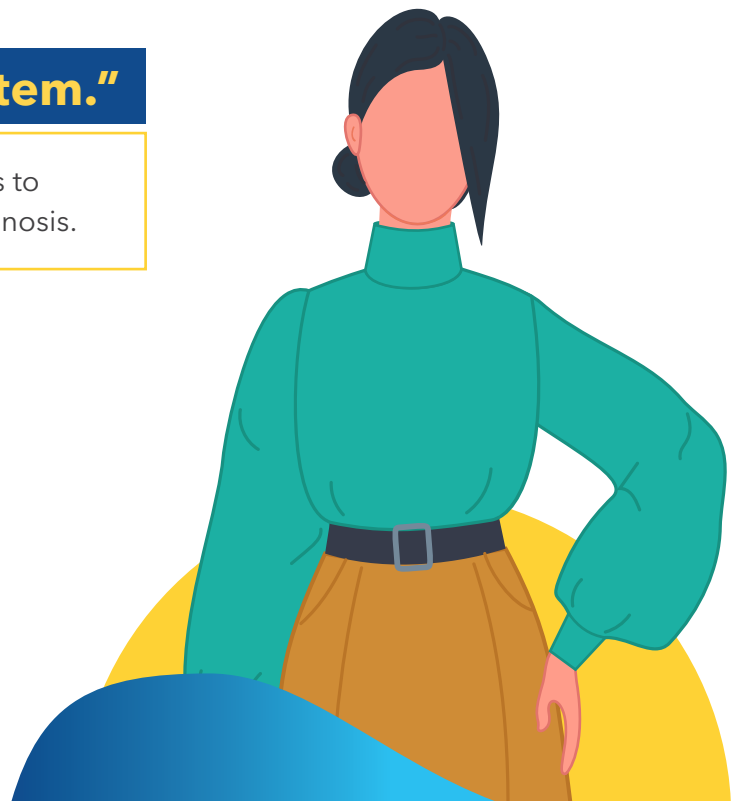
SUPPORT SYSTEMS ARE KEY

Patients' consistent top piece of advice they give to others is to make sure to have a support system after receiving a cancer diagnosis. Rebecca was in her late 40's when she was diagnosed with a Stage II breast cancer. She did, and still does, struggle with many common side effects like lack of energy, bone pain, nausea, hair loss, anxiety, depression, brain fog, and brittle bones.

Despite these side effects, Rebecca says her five years of treatment and care have been excellent. She credits her strong support system that includes family, friends, her community, programmatic financial support, and a quality health care team led by her oncologist.

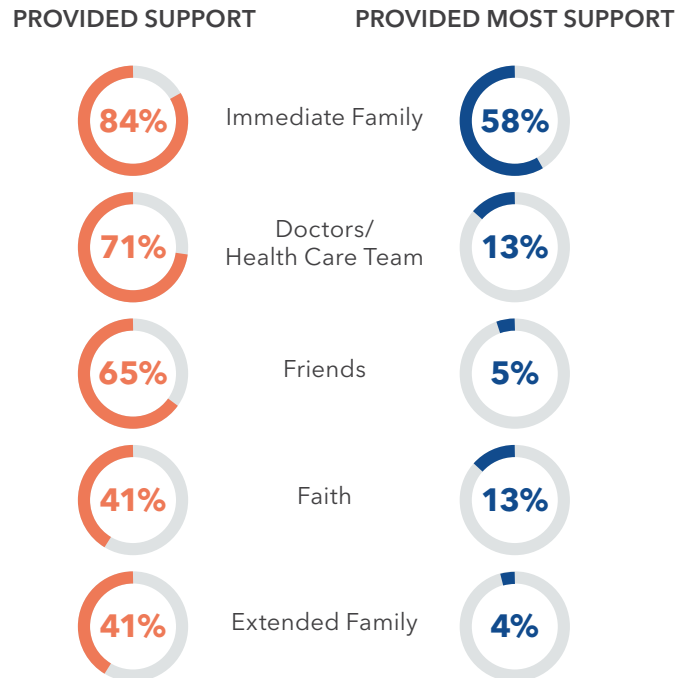
"Have a support system."

#1 Piece of advice given by patients to others after receiving a cancer diagnosis.



The sources of support Rebecca found mirror our survey data. Immediate family is a source of support for 84% of respondents. Doctors and health care teams were support for 71%, and friends were a source of support for 65% of patients. Other areas of support included faith (41%), extended family (41%), and work colleagues (20%). Other sources, including churches, advocacy organizations, support groups, and social media were reported by 20% or less of patients.

Sources of Support

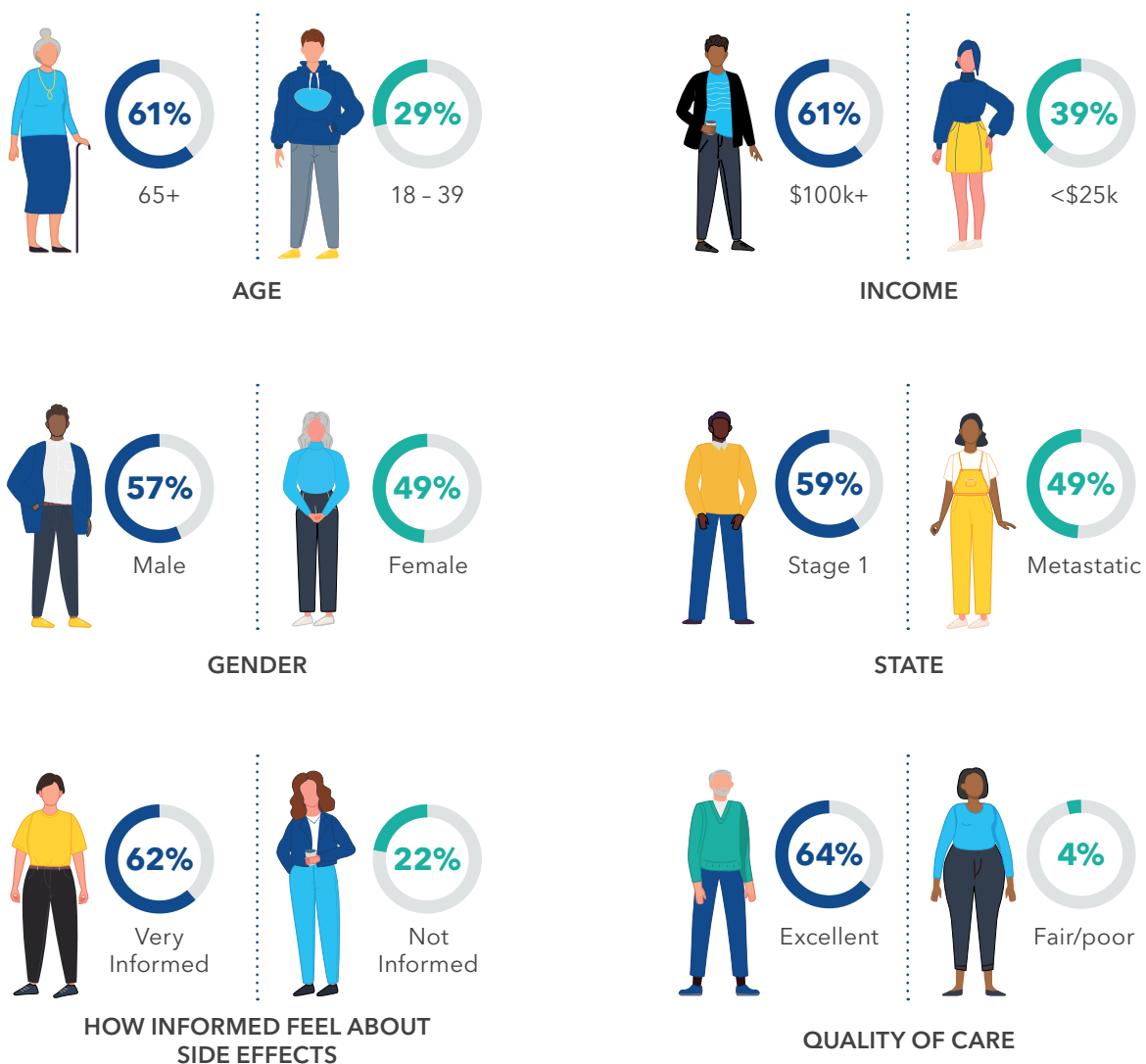


“ I had a team of friends. One took care of meals, connecting with other families. One was like my advisor, the person I thought everything through with. People just showed up and rolled up their sleeves and didn't even let me ask. When I look back, I just know how much love there is out there. It's hard to accept help when you are independent like I am, but I really had no choice.

About half of the national sample describe the support they received as excellent. However, the data continue to show large disparities along the lines of age, gender, income, how informed patients felt, and how they rated the quality of their care. Notably, perceptions of the quality of care align closely with levels of support. Among patients who rate the quality of their cancer care as excellent, 64% also indicated they had excellent support. On the other hand, among patients who rated their cancer care as fair or poor, only 4% felt they received excellent support.

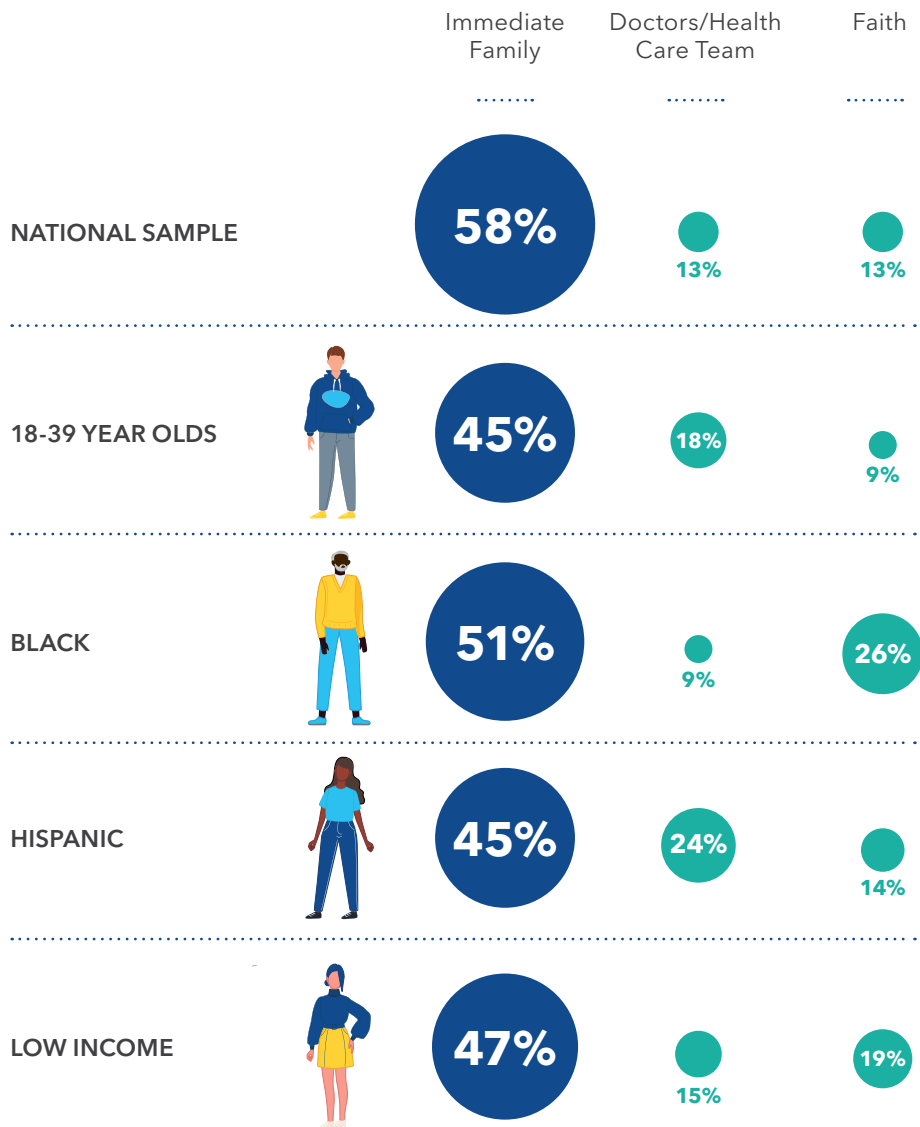
Similarly, of those who felt very informed about side effects, 62% said they received excellent support, while only 22% of patients rated their support as excellent when they felt they were not well-informed about side effects.

Respondents Who Rated Support as Excellent



Immediate family ranks highest in providing the most support among patients, 58% say it was their biggest source of support. Younger, Hispanic/Latino, Black, and low-income patients were less likely to depend on immediate family. And while Black and low-income respondents tended to lean on their faith more than other respondents, a larger percentage of Hispanic/Latino patients said they rely on their doctor/health care team for the most support compared to other patient groups.

Biggest Support Systems



Rebecca received strong support from her oncologist, whom she says was clearly steering the ship of her care and treatment. She cited numerous examples of compassionate and professional members of her health care team from radiologists, nutritionists, physical and mental therapists, along with aid workers who helped set her up on Medicaid to handle the medical costs.

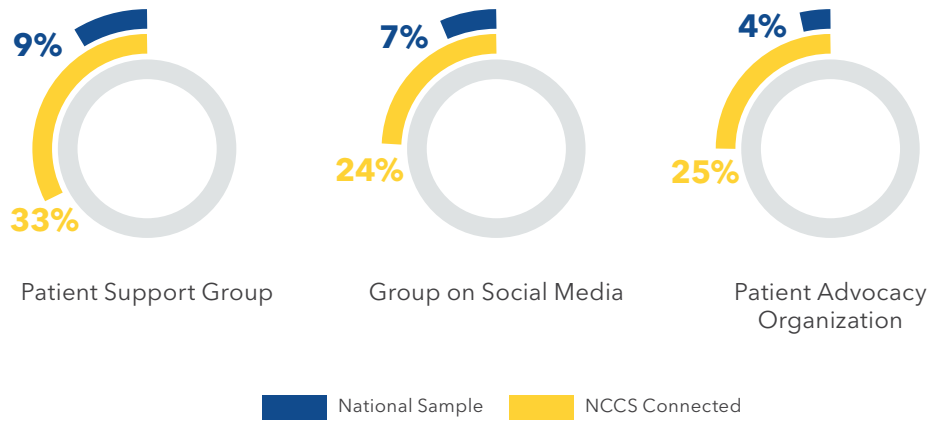
She had communities of friends who worked to set up meals, clean her house, drive her to appointments, and set up fundraisers. One friend even flew across the country on a moment's notice to provide emotional support. Her health care team told her they had never seen a patient with so much community support.

Rebecca's experience illustrates what the survey data show: when support systems are solid—a quality health care team, vested family and friends, programmatic financial support—patients have a higher chance at better experiences and outcomes.



As NCCS continues to advocate for equitable access to quality care and financial support, the data also show that we in the patient advocacy community need to reach more people. In the national sample, less than 10% said they found support from patient advocacy organizations, groups on social media, and patient support groups. Yet for NCCS-connected respondents, 24-33% said they found support in those spaces. While families and health care teams are, and should be, the best systems of support for most, patient advocacy organizations can provide additional systems of support by engaging more patients.

Connected Patients Access Support from Additional Sources

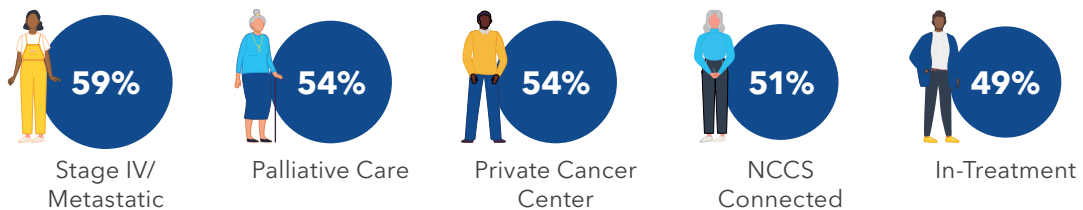


TREATMENT DURING COVID-19

As it did with everything else around the world, the COVID-19 pandemic affected care and treatment for cancer patients. Even though cancer centers made significant changes to protocols to ensure patients' safety, the vast majority of cancer patients (82%) believe their quality of care remained the same as before the pandemic, and 8% said their care was better.

The COVID-19 pandemic shifted many health care appointments into the virtual space. Four in ten respondents who had an appointment during the pandemic did so via telehealth services.

Used Telehealth Services

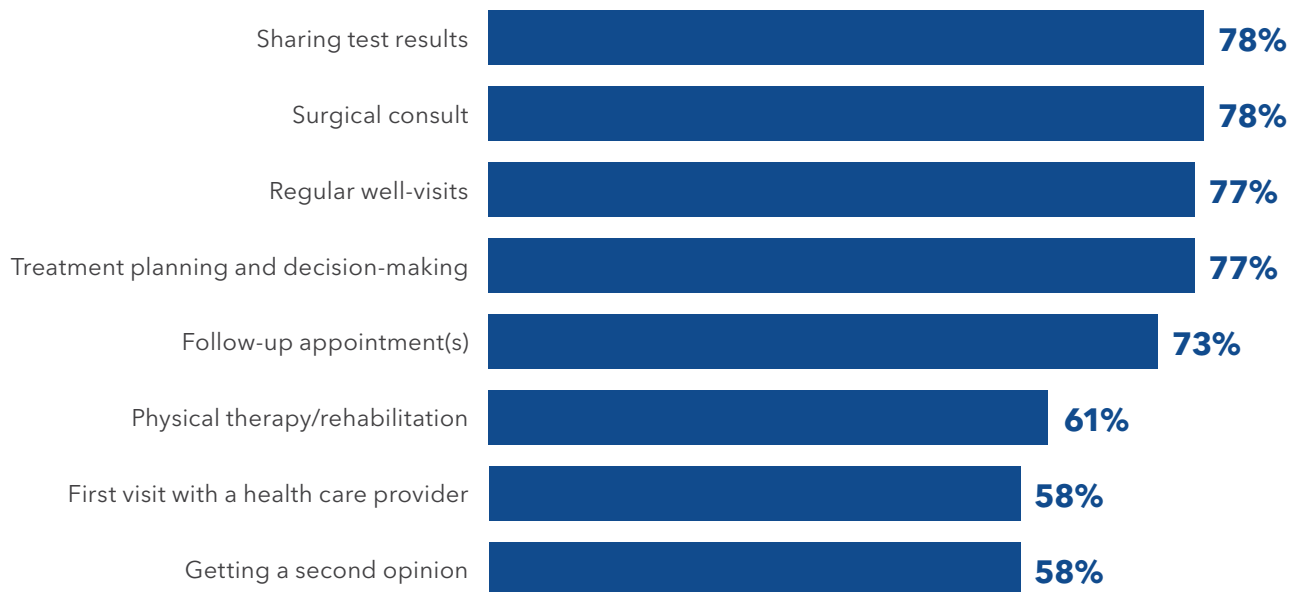


41%
of those with appointments had them via telehealth.



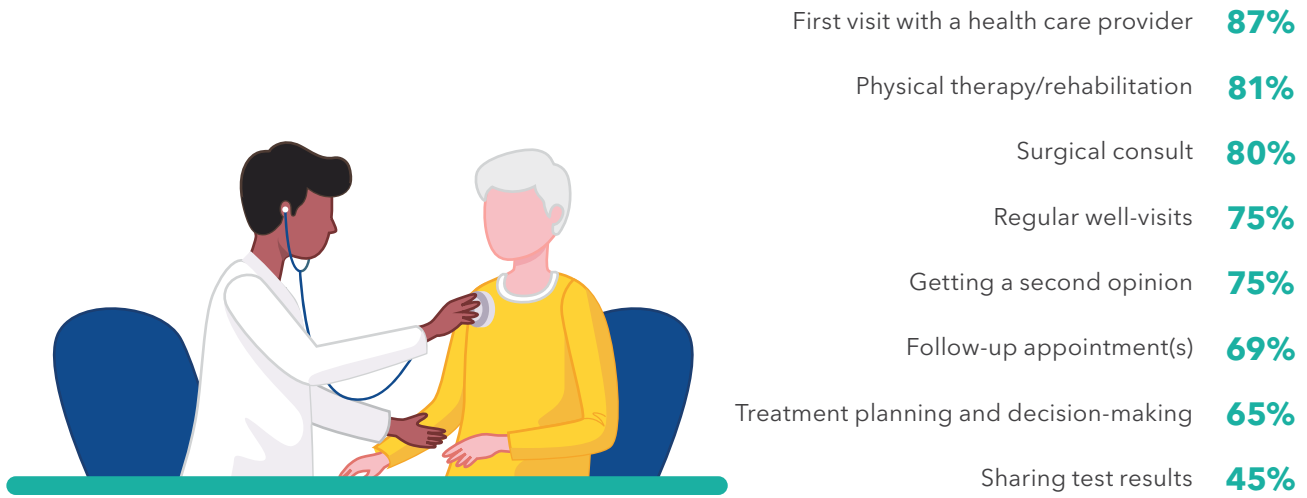
Sentiment on the quality of telehealth appointments varied based on the nature of the appointment. On average, three-quarters of patients rated their telehealth appointments as excellent/very good for follow-up appointments or regular well-visits, treatment planning, and sharing test results. Those numbers dipped to about 60% for appointments with more intricate purposes like physical therapy, getting second opinions, and first-time visits with a health care provider.

Telehealth Appointments Rated as Excellent/Very Good



Despite the relatively high satisfaction with telehealth appointments, the data also show that patients still prefer in-person appointments for most situations.

Preference for In-Person Visits over Telehealth



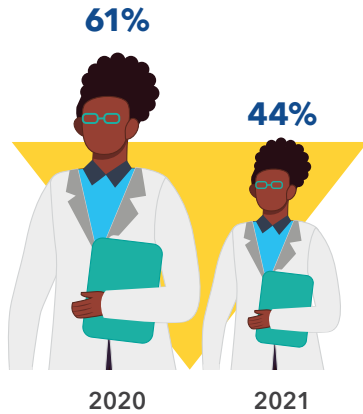
The data on care and treatment during the COVID-19 pandemic does leave room for interpretation in numerous ways.

One of our respondents, Roberto, is a 39-year-old Hispanic male who dealt with breathing and coughing issues for a month before going into his doctor fearing he had COVID-19. He did not have COVID-19, but he did have a tumor in his lung and was diagnosed with Stage II lung cancer. He credits COVID-19 with saving his life.

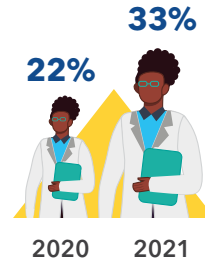
On the other hand, the cancer community at large has acknowledged that regular screenings have been down throughout the pandemic and there is concern about the long-term outlook of excess deaths over the next 10 years due to missed early detections.

The data did show a significant shift in patients' decision making mindset. While a "doctor knows best" mentality about treatment is still dominant, more cancer patients and survivors this year say they were involved in decision-making (up from 22% in 2020 to 33% today). There are also more people who actively researched all they could about their options and were aware about potential side effects from treatment. This could represent a shift to a more informed patient, and/or a response to changes in attitudes about health care during COVID-19.

Shift in Decision Making Mindset from 2020 to 2021



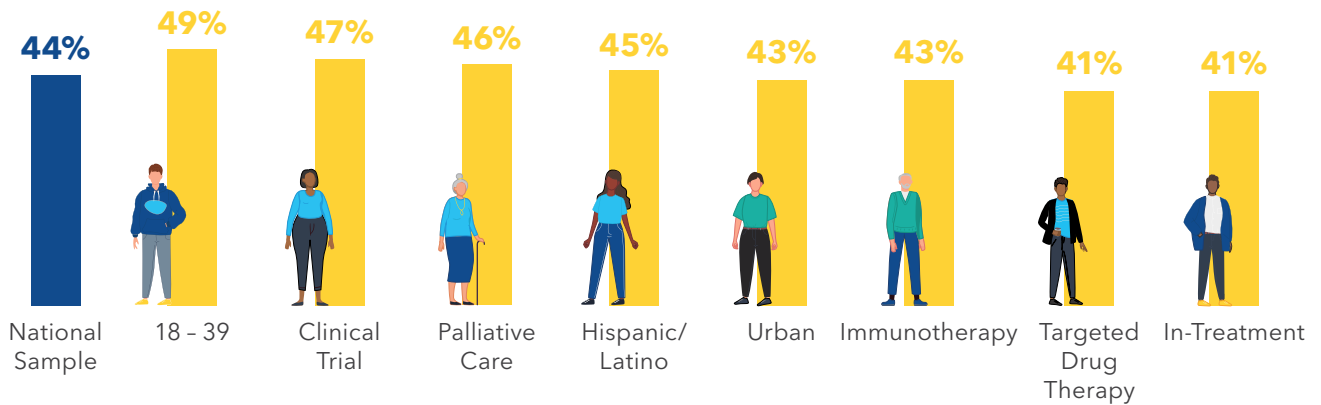
I rely/relied on the doctor to decide on treatment options and choose the best course of action.



I am/was very involved in researching and deciding on the best treatment options for me.

The data also show several groups even more likely to be heavily involved in deciding their treatment options.

Patients More Likely to Be Involved in Decision-Making



The lingering question is whether the COVID-19 pandemic played a significant role in the needle moving so significantly in this year-over-year data, or whether these mindset shifts are part of a broader trend in health care. We do not believe we can say either way at this time, but it is certainly a trend we will be watching.

MEANING OF SURVIVORSHIP

In 1986, the founders of NCCS brought about a different notion of the cancer experience. No longer would those diagnosed be looked at as passive victims, unable to do anything but hope for the best and wait until it was their time to succumb to a terrible disease.

These 23 men and women were a diverse representation of some of the most recognized experts on medical oncology, employment and disability law, health care consumerism, and psychosocial and behavioral research. Their vision was built around empowering and educating people on the full spectrum of issues related to living with, through, and beyond a cancer diagnosis.

The founders of NCCS did not see victims—they saw *survivors*.



Our definition of a survivor—from the time of diagnosis for the balance of life—has been the norm in and beyond the cancer community for 35 years.

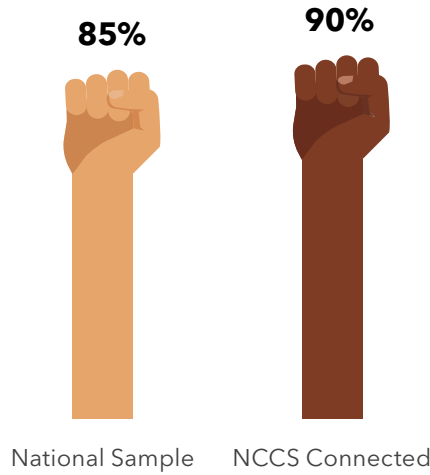
Over those three and a half decades we have seen a wide spectrum of sentiment about what it means to be a survivor. We know that some people with a cancer diagnosis do not feel comfortable thinking about themselves as a survivor. So, in our 2021 State of Survivorship Survey, we decided to ask how respondents felt about the word survivor.



Our data show two main takeaways:

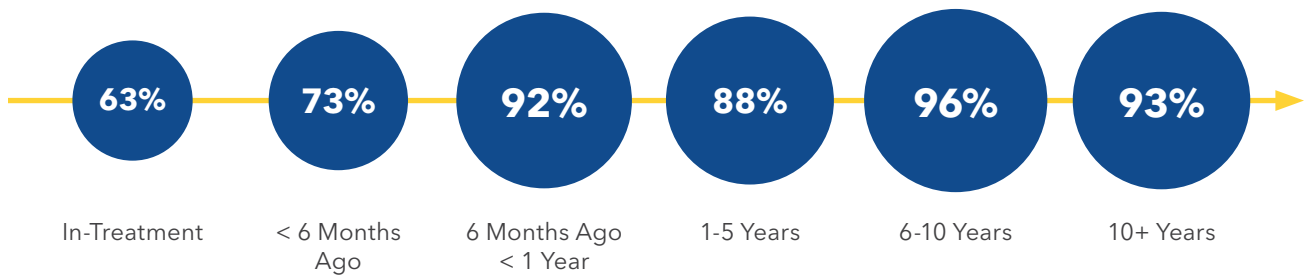
The term “survivor” remains highly resonant with 85% of the national sample saying they consider themselves a survivor and 90% of the NCCS-connected respondents saying the same.

The Term “Survivor” Continues to Resonate



Respondents’ comfort level with the term survivor increases over time. For those in treatment, 63% say they considered themselves survivors, while 93% of those 10+ years beyond treatment consider themselves survivors.

Identification with the Term “Survivor” Grows Over Time



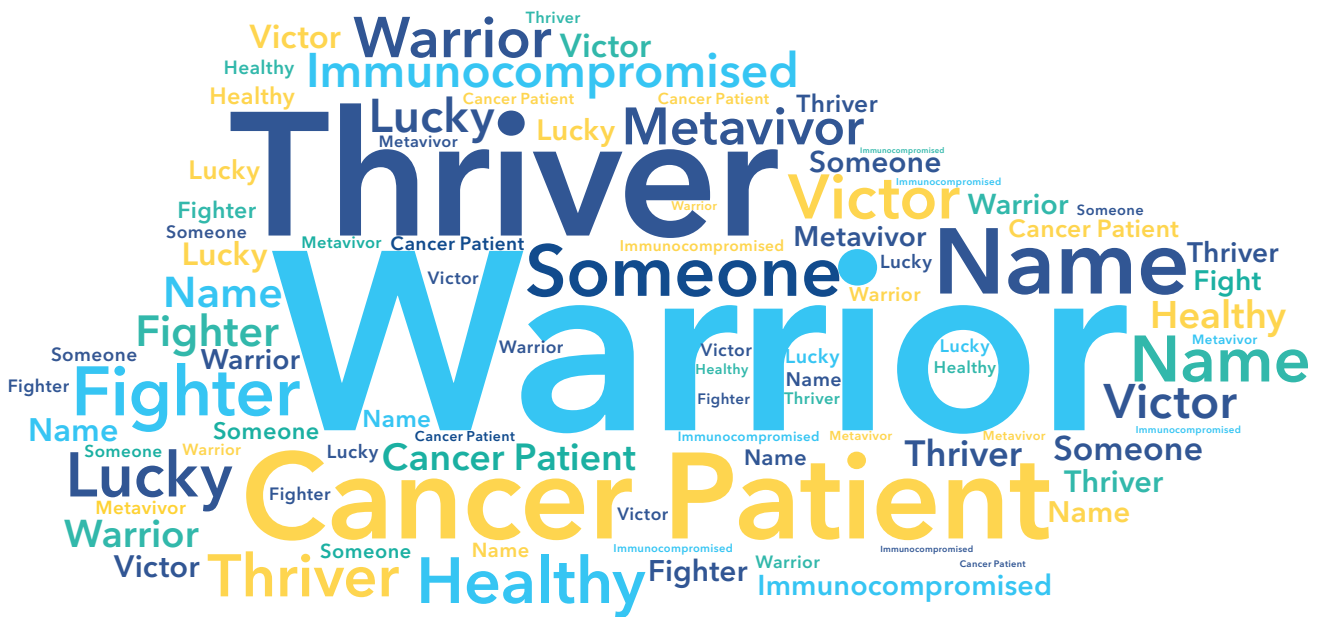
The data also show that a few feel the term survivor is not strong enough, as though just getting by is the goal instead of thriving. Others are uncomfortable using the term while in treatment or even after treatment as they face regular well-checks, perhaps fearful their cancer will return.



It seems past tense, but I don't feel like I will ever be done with it. Manage, live with it, keep getting tested, would rather use another word but don't know what it is.

- Male, 39, Stage 2

When asked about alternative words, the sentiment of thriving and battling shone through in responses.



When asked what the term “cancer survivor” means to you, the vast majority of respondents resonated with exactly what our founders envisioned 35 years ago—empowering people on the full spectrum of issues related to living with, through and beyond a cancer diagnosis.

I feel like anyone is a survivor once they receive a cancer diagnosis.


- Male, 59, Stage Not Discussed

I feel that anyone that fights cancer is a survivor... whether they win or lose the battle.

- Female, 60, Stage IV

Being able to live my life peacefully surrounded by family.

- Female, 75, Stage IV



“ Being a cancer survivor is like getting a second chance at life. It makes you feel differently about every decision you make. It also makes you feel incredibly lucky and gives you a new look on life.

- Female, 66, Stage III

CONCLUSIONS

Our 2021 State of Survivorship Survey provided us an invaluable opportunity to delve into the cancer patient and survivor journey from a range of perspectives and to better understand how NCCS can support our mission to advocate for quality care for all.

Notably, we were able to:



Build on and track our findings from 2020.



Better understand differences in patient attitudes, experiences, and needs between early and advanced stage cancer patients, with deep focus on metastatic patients.



Examine the data through a health equity lens, including both the experience of cancer care and financial concerns and sacrifices.



Learn about where patients find support and how it relates to their experiences and outcomes.



Identify telehealth expectations and experiences during COVID-19.



Understand the perceptions around the meaning of survivorship.

Throughout the survey data we found:



Most respondents found their care and treatment to be excellent/very good. The further removed from treatment, the more likely respondents were to rate it as excellent. Making it through, 'surviving,' is the biggest factor in how they rate their care.



Having a support system in place to help you throughout the journey is the top piece of advice from patients. While half of respondents say their support was excellent, younger, low-income, female, and metastatic patients reported having less support.



Significant disparities exist in the equity of and access to quality cancer care, with a disproportionate effect among the lower income, Hispanic/Latino, female, and young adult (ages 18-39) populations.



Most say the COVID-19 pandemic did not have a big effect on their treatment and 40% were able to have telehealth appointments with their care providers. Most still prefer in-person appointments to telehealth.



The physical, emotional, and financial costs of cancer are shared by all cancer survivors, but younger, Hispanic/Latino, and female patients disproportionately report these effects.



Metastatic/Stage IV patients often have different priorities in care, particularly when it comes to quality of life.



NCCS-connected respondents had higher expectations in their assessments of quality care, were more likely to feel empowered to be active in their care and were better able to find a range of support systems.



The 2021 State of Survivorship Survey demonstrated that when patients receive coordinated and quality care from their health care team, have excellent support, and have financial resources or assistance to alleviate worry about medical costs, they are more likely to have positive experiences and outcomes.

However, younger, female, Hispanic/Latino, low-income, and metastatic/Stage IV patients are less likely to receive coordinated, quality care and less likely to have the support they need.

We must continue to:

Advocate

for change in how the nation researches, regulates, finances, and delivers quality cancer care and work to pass the Cancer Care Planning and Communications Act.

Empower

cancer survivors and patient advocates through our publications, tools for self-advocacy, and programs, like the Survivorship Checklist, the Cancer Policy & Advocacy Team, and Elevating Survivorship.

Convene

advocates and cancer organizations to address nationwide public policy issues affecting cancer survivors.



NCCS represents more than 17 million Americans who share the survivorship experience—living with, through, and beyond a cancer diagnosis. Our 2021 State of Cancer Survivorship Survey shows us where there are gaps in care and support, resulting in unequal outcomes for cancer survivors. Our work has never been more urgent.



NATIONAL COALITION
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